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ABSTRACT

In spite of the growing awareness and development of respite services, many families in need of them have little or no access. This is especially true for families whose children have emotional handicaps. A rationale for respite services supports parents' entitlement to respite care, its importance to all family members, and its help in improving family effectiveness. Respite services consist of in-home care, which may include homemaker, sitter/companion, and parent trainer services; and out-of-home care, which encompasses care in the provider's home, foster care or licensed family care, group day care, group home residential care, respite care provided by residential treatment facilities, crisis nurseries and emergency respite care facilities, and community services providing respite care as a secondary purpose. Attributes and training required for respite providers are outlined. Public policies have restricted development of respite care, by creating: eligibility criteria which exclude many families, inconsistencies in funding, and other conditions of service. Efforts are being made at many levels, from local advocacy groups to federal legislation, to bring respite care into the service delivery system. The report concludes with a list of 59 references, containing both published and organizational sources. (JDD)

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Respite Care:

A Monograph

Families as Allies Project
Research and Training Center to Improve Services
for Seriously Emotionally Handicapped Children
and Their Families
Portland State University

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RESPITE CARE:
A MONOGRAPH

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FOREWORD

Preparation for this monograph began with a search for respite care programs that serve families whose children have serious emotional disabilities. The search was not very successful. Discovering individual respite programs (such as the R and R Program in Spokane, Washington) that successfully serve families whose children have emotional or behavioral problems was exciting and encouraging. There is no indication, however, that such programs are widely and easily available throughout the country.

Although there are few respite care services in the area of emotional and behavioral disorders, there has been strong advocacy for respite care in other areas, particularly in the field of developmental disabilities. Programs have also been developed in the field of child welfare to provide respite care to families facing severe crises or whose children are at risk of abuse or neglect. Accordingly, our search turned in those directions. There are significant differences between the areas of developmental disabilities, child welfare and emotional handicaps; however, it is apparent that the ideas and programs developed in each are often transferable and provide excellent models on which to build.

Beginning in the Spring of 1987, contact was made with over forty respite care programs located throughout the country. The programs were located through resources such as journal articles or newsletters, and by referral from parents and professionals involved in specific respite care programs. We initially asked each contact person, "Does your program serve children whose primary problem is an emotional or behavioral disorder?" Most often the first question was answered in the negative. Nonetheless, everyone (including parents of children with emotional, behavioral, and/or developmental disabilities, as well as the directors, supervisors and staff of many kinds of programs) had much to offer. Some of them described very successful and growing programs; others recounted the disappointment and frustration of seeing an effective respite care program end as funding ran out and could not be replaced.

Two clear themes ran through all of the discussions: (1) respite care is a very vital and substantial support to families whose children have special care needs; and (2) there are neither enough respite care services nor consistent public support for their development and maintenance. Even though the discussions often involved issues such as insufficient support for programs, it was still very encouraging to be in contact with so many individuals concerned that respite services be made available to families, including families whose children have emotional handicaps. It became evident that respite care is being recognized as an important and needed service, and that committed and energetic people are working to make respite care services a part of our social service system.

INTRODUCTION

Respite care has been defined as the provision of temporary care to persons with disabilities, with the primary purpose of providing relief to caregivers (Warren and Cohen, 1985, p. 66). This description points out a significant feature of respite care services: the benefits are intended for the caregivers, not only for the individual with a disability. Wikler, et al. have described the goals of respite care as being:

> 1) to provide refreshing, energizing breaks that will increase the family's ability to carry out home care while decreasing the emotional costs to its members; 2) to maintain the optimism and loving that the family member as caregiver can best provide; and 3) to avoid burnout that may precipitate neglect, major family disruptions, or placement. (Wikler, et al., 1986, p. 258).

As an accompaniment to trends in deinstitutionalization and home-based care, families caring for frail elderly members or members with physical or developmental disabilities have, over the last ten years, increasingly demanded respite services (Castellani, 1986). In some cases, families have felt that without respite services they would be unable to care for the person with disabilities in their home (Cohen, 1982). Parent demand, along with recognition by professionals of the positive role respite care can play, has led to a growing number of respite care programs.

Researchers, parents, and program developers are documenting the successes and problems that characterize respite services in the literature They are also introducing respite care into the public policy-making arena and the political process (Castellani, 1986; Sullivan, 1979). As claims are made that respite care can help to reduce stress in families (Wikler, 1986), prevent child abuse and neglect (Subramanian, 1985), and be a vital support to families with a member who would otherwise be institutionalized (Cohen, 1982), there has been growing awareness, development, and refinement of respite services.

In spite of this growth, many families in need of respite services have little or no access to them. This is especially true for families whose children have emotional handicaps. Researchers surveying respite care programs have found that individuals with emotional or behavioral problems are often excluded from services (Slater, 1986; Upshur, 1982). Moreover, respite providers trained to work with children who have physical or developmental disabilities are frequently not prepared to deal with special emotional or behavioral needs (Cohen, 1982).

This writer, in a review of forty respite care programs, found that when families whose children have emotional handicaps do receive respite services, it is most often only if the child has a primary diagnosis of developmental disability. Although respite care programs designed specifically for families whose children have emotional disorders do exist, they are very limited in number.

The small number of respite services for children with serious emotional disturbances is unfortunate because families whose children have emotional handicaps face many of the same difficulties as those whose children have other disabilities--and they are as much in need of respite services. Just as a child with special medical needs may require twenty-four hour supervision, a child whose emotional problems lead to impulsiveness and poor self-control will also call for constant attention from parents. Similarly, respite services are needed by parents facing the physical demands of caring for a non-ambulatory teenager, just as they

are needed by parents with the exhausting tasks of dealing with constant over-activity, tantrums, or other problem behaviors often seen in children with emotional handicaps.

This monograph is written with the purpose of facilitating the development of respite services for families whose children have emotional handicaps. The rationale for respite services will be discussed, and information based on a review of the respite care literature, will be presented about the types of respite care programs that have been developed. Recruitment and training of respite providers will be described. Policy, funding, and program development issues relative to provision of respite care will also be reviewed. Various issues will be illustrated throughout the monograph with descriptions of programs providing respite services to families.

Because little has been found in respite care literature or in existing programming that specifically addresses the needs of families whose children have emotional handicaps, we have relied upon the experiences of researchers, parents and service providers in other fields. Particular reliance has been placed on research and program development in the field of developmental disabilities.

A great deal of what has been learned about providing respite care to families who have a member with developmental disabilities is very applicable to service planning for families whose children have emotional problems. While the unique needs of both groups must be considered, the experiences and insights of children with developmental disabilities, their parents, respite workers and the other professionals involved with them provide a sound basis on which to build.

Terry E. Butler, M.S.W

RATIONALE: THE NEED FOR RESPITE CARE SERVICES

Right to Support: Parents' Entitlement to Respite Care Services

The importance of respite services to foster parents caring for children with emotional handicaps and other special needs has been recognized for some time. Arkava (1978) has asserted that foster parents face exceptional demands, including: (1) the long-term commitment of caring for a child with handicaps; (2) the emotional and physical demands of providing repetitive and routine care; (3) the restrictions on foster parents' mobility; and (4) the difficulties of finding appropriate babysitters and time away from routines. Natural parents, too, face the same conditions and can potentially function at their best if given occasional relief.

Recognizing a need by foster parents for respite services suggests that those services would be at least equally important and beneficial to natural parents. If provision of respite services can enhance foster parents' caregiving ability, then provision of those services to natural parents--before their children are placed in foster care--may allow more children to remain in their own homes.

An important concern among respite care providers is that their services be used by all of the families that need them. Although respite care services have been shown to benefit families of children with disabilities, and are perceived favorably by many families (Upshur, 1983), there continues to be a hesitancy on the part of some parents to use those services. Halpern (1985) noted that low income, minority, and young families were often unaware or cautious about respite services, and recommended outreach efforts to those families by agencies providing respite care.

Some of the parents participating in the project carried out by Wikler, et al., were found to have difficulty openly expressing their need for relief. According to the authors, "It was as though a 'good' mother should never complain about her own exhaustion or frustrations" (Wikler, et al., 1986, p. 250). The authors identified problems with this perspective. First, a parent may not be able to monitor his or her own exhaustion level and so may suddenly find that he or she is emotionally depleted, and second, a parent may feel that he or she is being judged inadequate as a parent by requesting respite services.

Curran and Bongiorno (1986), both of whom have children with developmental disabilities, encourage parents to use respite services. They believe it is vital that parents recognize the signs of their own fatigue and stress, and that they realize the importance of respite services to themselves and their children.

> The major caregiver needs to feel that he or she is *entitled* to respite. There needs to be an understanding that this parenting job is more demanding than more typical situations. Lack of adequate services 'forces' parents and their child/adult with disabilities to spend more time together than is healthy for either one. This dynamic can increase the tendency toward dependency by the individual with disabilities and overprotectiveness by the parents. Respite care can help promote healthier individual and family functioning. (Curran and Bongiorno, 1986, pp. 92-93). (Emphasis in Original).

Parents are not the only ones to benefit from respite care; respite services can also address the particular needs and concerns of the brothers and sisters of a child with disabilities. As Powell and Ogle (1986) have pointed out, respite

services can be important to siblings in at least five major ways: (1) by allowing them to renew relationships with parents; (2) providing time for their participation in special activities; (3) allowing siblings time for themselves; (4) enabling families to take short vacations; and (5) keeping the family system intact. Thus, respite services can benefit not only a child with a handicap, including an emotional handicap, but that child's entire family.

Stresses and Demands of Special Care

Much of the respite care literature has focused on the particular stresses experienced by families whose children have handicaps. As Salisbury (1986a) has pointed out though, all families experience times of stress, especially as parenthood brings changes in the way individuals function and structure their lives. The effects of the stressors accompanying parenthood have traditionally been mitigated by reliance on extended family or community support (McCubbin, et al., 1980). The presence of those resources has, however, been reduced in many cases by changes occurring in family structures and roles, as well as by economic and social changes that have reduced the availability of family or social support (Cohen and Warren, 1985). It is no longer unusual, for example, for families to live far from any relatives, and to live in areas where neighbors do not know each other, and do not serve as resources for mutual assistance.

When a family has a child with emotional or behavioral problems, feelings of stress and the need for support can be intensified. Frequently, things taken for granted by other parents are difficult to obtain or no longer available. Finding babysitters able to deal with the child's special needs, for example, may be very difficult. Even relatives or close friends may be unable or unwilling to care for the child. If the child's problems involve overactive or aggressive behaviors, routine tasks such as shopping or keeping medical appointments can be extremely difficult. Visiting friends, going out to dinner or a movie, or simply having a few relaxing moments at home may occur infrequently or not at all.

The family of a child with emotional or behavioral difficulties may find that these difficulties contribute to the family's experiencing the isolation sometimes found in families whose children have developmental disabilities (Wikler, et al., 1986). Along with this decreased social activity, other stressors frequently faced by families whose children have handicaps were noted by Wikler and her colleagues. Among these were the persistence of physically exhausting tasks (such as managing a child with hyperactive behaviors), the prolonging of the child's dependency needs beyond those of other children, and few caregiving breaks (Wikler, et al., 1986). Both Wikler, et al., in a project involving families whose children have developmental disabilities, and Subramanian (1985), through a study at an emergency care facility for families whose children were at risk of abuse or neglect, found that respite care services served to buffer the effects of these stressors while bringing about a reduction in families' measured levels of stress.

Balancing the Demands of Special Care

Although discussion of respite care is frequently focused primarily on the stress experienced by families, respite care can also be related to overall effectiveness in the task of parenting a child with special needs. Recognizing the

extent of that task, Cohen and Warren have described resources needed to balance the demands of parenting:

> *Good physical health* and stamina, because caring for a severely impaired child is physically demanding.
> *Good mental health*, because living with the recognition that a child will always be disabled is a difficult task.
> *An emotionally strong marriage and healthy family interaction patterns*, because the demands of being the family of a severely disabled individual will exacerbate any tensions or strains that exist in a marriage or in other family relationships.
> *Time*, because caring for a developmentally delayed child takes lots of it, every day and every year for many years.
> *Money*, because it can buy needed services, more accessible physical facilities, equipment, and adaptive aids.
> *Skill* in negotiating the service system, which is closely associated with educational level, because it can result in a variety of services that lighten the burden of care.
> *A support network of family and friends*, because such a network can provide the love, comfort, and help that families of the disabled need. (Cohen and Warren, 1985, pp. 8-9).

As Cohen and Warren point out, families with all of these resources are rare, especially as social changes reduce the availability of family and social supports. Access to those resources is further reduced by factors such as the increasing number of births to adolescent mothers, the fact that many of these births are to young women with very low incomes, the growth of single parent families, the significant proportion of children--especially black children--living in poverty, and the fact that half of the women in the country are employed outside the home (Cohen and Warren, 1985).

The need for respite care goes beyond reduction of stress. Clearly, many families whose children have handicaps are in need of services providing supplementary support in order to most effectively care for their children. Respite care is one of those services. Although the need for services by low income and young families may be more acute, all families whose children have handicaps can benefit from the relief offered by respite care. This is evident when reviewing the three previously mentioned respite care goals set forth by Wikler, et al. (1986): increasing the family's ability to provide care while decreasing emotional costs to the family; maintaining the optimism and love best provided by the family; and avoiding burnout that might precipitate neglect, family disruptions, or institutional placement.

Respite care is supportive of family effectiveness in more specific ways as well. Using respite services means that individual family members can have time to themselves as well as socialize and participate in the community more frequently, go to medical and dental appointments, pursue their own interests and personal growth, experience reduced levels of stress and pressure within the family, and reduce the dependence of the person with a disability (especially an older child) on the family.

Improved coping abilities and attitudes have also been reported by families using respite care. According to one parent whose child has handicaps, knowing that there will be a break in the tasks of continuous care enables parents to maintain their energy levels and motivation when faced with demanding situations (Gordon, personal communication, 1987). In some cases, improved family perceptions of the person with a disability were related to provision of respite care (Intagliata, 1986).

VARIED RESPONSES TO VARIED NEEDS: LOCATIONS AND TYPES OF RESPITE SERVICES

Respite services are often described as being of two general types: in-home care and out-of-home care (Levy and Levy, 1986; Upshur, 1982). Of these two models, in-home respite care has been found to be the model most frequently preferred by parents (Cohen, 1982; Warren and Cohen, 1985; Slater, 1986; Upshur, 1983). As many parents, researchers and program developers have pointed out, however, respite care programming calls for flexibility in providing a wide range of services that are accessible to as many families as possible (Cohen, 1982; Upshur, 1983; Curran and Bongiorno, 1986; Wikler, 1986). Since families and children vary widely in their backgrounds, experiences, and needs, limiting services to one type can limit access to include certain families, while excluding others whose needs are just as great.

In the remainder of this section, methods of delivering the range of in-home and out-of-home services are discussed, along with the advantages and limitations of each. Figure One (see page 10) outlines and briefly summarizes some of the types of respite care services.

In-Home Services

In most cases, in-home care involves the provider coming into the family home to care for the child with disabilities, allowing the parents or other caregivers the opportunity to leave the home for a predetermined amount of time. Levy and Levy (1986) describe three models of in-home respite care services. These are: homemaker services, sitter/companion services, and parent trainer services using informal helping networks. A fourth model, in which parents and providers are in the home together, will also be discussed.

A. Homemaker Services

Homemaker services are those provided in the family home by a trained and licensed employee of a home care agency. According to Levy and Levy, these services typically are available seven days a week, twenty-four hours a day in flexible shifts. Respite care under this model may be provided on a planned or emergency basis, with parents most often leaving the home while the child receives care. Cohen and Warren (1985, pp. 67-68) describe a project carried out from 1981 to 1983 by the National HomeCaring Council, an agency working to improve home aide services, which demonstrated that homemaker services could provide:

> -assistance with the personal care of the person who is disabled;
> -help in coping with unusual problems and crises; [and]
> -periodic relief from the continuing intensive demands that care of the individual may require.

FIGURE ONE: TYPES OF RESPITE CARE SERVICES

1. **IN-HOME CARE**: Provided in the family's home, usually by one person.
   - **a. Homemaker**
     Generically trained for a variety of tasks in the home;
     Often available on an emergency, 24-hour basis;
     Provider may change from session to session.
   - **b. Sitter/companion**
     Specifically trained to provide care to children with handicaps;
     Respite provider available on a planned, as-needed basis;
     Usually one care provider matched to a family.
   - **c. Parent trainer/informal helping network**
     Similar to sitter/companion model, with provider chosen by the family and trained by the respite care agency.

2. **OUT-OF HOME CARE:** Provided outside the family home in a variety of settings, by a single provider or a group of respite care staff.
   - **a. Provider's home**
     Involves an individual or family taking the child into their home for a specified amount of time;
     Frequently provided by volunteer families, or among parents through a parent cooperative model.
   - **b. Foster care or licensed family care**
     Usually involves some level of training, certification and monitoring by a public agency
   - **c. Group daycare**
     Located in a central facility, often a church, school, or community center;
     Care provided to several children at once by trained staff;
     Normally available during working hours or on weekends.
   - **d. Residential respite care**
     Involves a small number (4-12) of children being cared for in a home-like setting;
     Stays can be for a few days or up to a month;
     Provides more highly trained staff and availability of backup services.
   - **e. Respite care provided in residential care facilities**
     Involves otherwise longer-term facilities providing a certain amount of respite care beds;
     Provides highest level of staff training and backup services.
   - **f. Crisis nursery and emergency care facilities**
     Most often provided for families whose children are at risk of abuse or neglect, or who are facing crisis situations causing them to be temporarily unable to care for their children;
     Can serve as models for provider training and coordination of respite with other services.
   - **g. Generic community services**
     Services normally available to most members of a community, and which provide families with a temporary break from caring for their children;
     May include schools, camps, team sports, after-school activities, recreation programs, etc.;
     Services are often not available to children with disabilities, but can be a form of respite to these children's families, as they are to the families of children who typically use them.

B. The Sitter/Companion Model

Levy and Levy describe sitter/companion services as differing from homemaker services primarily in that a family is usually matched with a single care provider who offers services on a planned and as needed basis. They note that this promotes continuity in the relationship between the provider and child, and the provider and family. This allows for supplemental benefits such as the family, respite provider and child formulating and working on behavioral or other goals during the delivery of respite care.

The sitter/companion model also differs from homemaker services in the area of training: in most cases the provider is trained to work with specific disabilities, rather than to deliver more generic care. This difference is very important, since training which parents perceive as relevant and of high quality will enable them to feel comfortable using respite services (Cohen, 1982).

The sitter/companion model is one of a variety used by the Brown County Respite Care Program in Green Bay, Wisconsin. The program also follows procedures which illustrate how individual respite workers and families can be optimally matched. Respite providers are recruited through local colleges or other community resources and trained by the agency to care for persons with a variety of disabilities, including emotional handicaps. Once services are arranged, providers are paid a daily rate by the families themselves (Jan Lapacz, personal communication, 1987).

Prior to placement of a respite worker, the program coordinator visits the family's home to assess the needs of the person with disabilities. The coordinator selects a care provider with the appropriate skills to meet the identified needs, and a pre-placement visit to the home by the provider is arranged. At that time the coordinator, parents or other caregivers, the person receiving care, and the provider determine if the match is appropriate. After respite has been given, the caregiver and the provider complete an evaluation form which is reviewed by the coordinator.

Respite providers working with the Brown County program care for clients for periods of twelve to fifteen hours, and carry out a variety of responsibilities in the home. Along with being a companion to a child or adult with disabilities, and giving whatever specialized care that person needs, providers' tasks may include household chores, preparing meals, transporting the client, or other activities arranged between the worker, client and caregiver (Brown County Respite Care Program, Respite Care Provider Packet, 1987).

The range of provider responsibilities and activities found in existing programs demonstrates that respite services can be planned to accommodate a variety of needs and accomplish many objectives. Respite care programs vary in the tasks required of respite workers. In some cases workers are expected to provide routine care, or to carry out activities with the person with disabilities, and are not expected or authorized to perform household chores. Other programs may give respite providers full responsibility for management of the household and the care of siblings. In one project carried out by Wikler, et al., a primary task of the respite provider was to help the child achieve specific behavioral goals (Wikler, et al., 1986).

C. Parent-Trainer Services: Using the Informal Network

Adequate and specific training, along with consistency in the provider-family-child relationship can make the sitter/companion model of in-home respite care compatible with the needs of families whose children have emotional handicaps. This is also true of the third in-home model described by Levy and Levy (1986), which they called parent trainer services. According to the authors, parent trainer services and the sitter/companion models are similar in that the respite care provider is trained to work with the child's specific disability, and the same person consistently delivers the service. This model differs, though, by using the family's informal support network. Relatives, friends, and neighbors can be recruited, trained and paid by the respite agency to provide respite services. In addition, Levy and Levy note that the model includes parent participation in training, which ensures that their information on the child and expectations for care are shared with the provider.

Young and Mason (1987), of the Portland Research and Training Center's Therapeutic Case Advocacy Project, have described the importance of integrating the family, social, and service supports surrounding a child with emotional handicaps into that child's system of care. The parent trainer model of in-home respite care facilitates this by involving significant family and social resources. Especially when coupled with high quality training, the use of familiar care providers chosen by the family addresses the need parents share to feel comfortable and positive about the care their child receives.

The respite programs reviewed for this monograph most often employed the trained sitter/companion model in which the respite workers were recruited and matched to the family by the respite agency. Several of the program staff interviewed, however, recognized that families were using, or would prefer to use, a family member or friend to provide respite care. In some cases, programs responded by training and paying providers chosen by the family. Curran recommends this as an option families ought to pursue, since they are the best judges of who should work with their child. She suggests that caregivers be encouraged to locate good babysitters, who may be eligible for training by the respite agency. Curran notes that she and other parents whose children have handicaps are more likely to use respite services if they are comfortable with the respite providers (Curran and Bongiorno, 1986). Slater (1986) corroborates this by citing survey findings indicating that whether agency provided respite services were available or not, caregivers preferred using members of their family network to care for their children with handicaps.

D. Modeling Skills for Parents and Providers

A fourth model of in-home respite care service involves the presence of both parents and respite providers in the home during the respite period. The service was designed by the Center for Children and Parents in Anchorage, Alaska for a specific group of families whose children were at risk of abuse or neglect. As part of that agency's Child Protection Respite Care Project, parents attending parenting skills classes remained home while the respite provider worked and modeled parenting techniques. A goal of the overall program was to provide relief to parents by having someone care for the child, while simultaneously improving the parents' skills (Final Report, Child Care Respite Care Project, 1987).

While in this case modeling was in a single direction, it would also be possible for modeling to be effectively exchanged as part of training between both

respite workers and primary caregivers. Just as the Alaska project included modeling by trained persons to enhance parents' functioning, in more general populations of families whose children have handicaps, care providers could learn by modeling the techniques and strategies used by parents.

E. Advantages and Limitations of In-Home Respite Care

There are advantages and limitations to the provision of respite care in the client's home, some of which have been described by Levy and Levy (1986) and by Upshur (1983). Among the advantages attributed to in-home care are:

(1) The child receives care in his or her natural surroundings; therefore time does not have to be spent adjusting to a new environment. This means that the establishment of a positive relationship between the child and respite provider can occur in a normalized atmosphere and be more easily maintained. Ptacek, et al. (1982), found that this was important to the families involved in their study.
(2) Specialized equipment or adaptations to the home designed for the child do not have to be transferred to another setting.
(3) Transportation does not have to be arranged by the parents or other caregivers.
(4) In-home services can be relatively inexpensive. Upshur notes that providers are paid only for training time and when actually delivering services, and that fixed costs are generally limited to payment for a program coordinator.
(5) Providing in-home respite care allows more flexibility in the age range and kinds of handicaps of the children served.
(6) In-home respite services allow the option of providers caring for both the child with handicaps as well as his or her siblings. If this is part of the caregiver/agency agreement, the respite period can be much more of a "break" for parents.

Limitations to in-home respite care described by Upshur and by Levy and Levy include:

(1) The issue of where the family members will go. This can be a particular problem for low income families. Some programs do provide funds or activities that assist the family in leaving the home, but this is not always the case.
(2) Caring for a person with very severe behavioral or medical difficulties in the home, especially by a lone individual, may be inappropriate. In addition, unless the provider is very highly trained, some families may feel uncomfortable leaving their child in his or her care.
(3) Some cost effectiveness may be lost by serving a client individually rather than in a group.
(4) Services delivered away from an agency and in a variety of locations are more difficult to monitor, supervise and evaluate.
(5) Respite workers, who are often low paid and work part time, may find transportation to the client's home difficult or costly.
(6) Respite care provided in the home by a single provider is less likely to be accessible in an emergency, or on short notice, than a

residential facility with round the clock staff. Also, since respite providers have their own ongoing personal and family responsibilities, it may be difficult for them to be in a client's home for overnight or longer periods of care.

Many issues need to be considered when respite care is provided in the child's/caregiver's home. For example, liability concerns and procedures should be clear to caregiver and provider. Parents may be required to carry insurance which covers injuries received by the respite provider; the provider may need his or her own insurance; or the respite care agency may maintain insurance coverage for respite providers and other staff. If transportation of the child by the provider is involved, there may be special liability concerns.

Before respite takes place the caregiver, respite provider, and respite agency should be mutually clear about the following: (1) the respite care provider's use of appliances or other family property in the home; (2) use of the caregiver's car; (3) the respite provider's responsibility for meals and routine household chores; (4) whether the respite provider is responsible for siblings of the child with a handicap, or for the child's friends; particularly if the relationship between the child and provider is meant to be consistent and an important part of the respite service; (5) whether one provider is regularly assigned to the child or whether the provider changes; (6) the respite provider's and/or caregiver's responsibility to plan activities for the child; (7) how responsibility for breakage of provider's property by the child, or family property by the provider will be determined; and (8) how far ahead respite care is planned between the caregiver, provider and agency, and what the mechanisms are for scheduling respite caregiving.

As mentioned earlier, many of those working to promote respite care services for families whose children have handicaps call for an array of programs to meet the needs presented by caregivers and the community. These services may be coordinated by a single agency, such as the Oh What A Relief It Is (OWARRII) program described by Cohen and Warren (1985, pp. 79-80). That program provides nine types of respite services ranging from sitters to pediatric hospital respite placement. Most programs, however, specialize in one or two kinds of service, such as in-home care and group day care outside the home.

Out-of-Home Care

Out-of-home respite services can accompany in-home services or be designed to meet particular purposes of their own. Care provided outside of the family's home may be more appropriate, for example, when the family--by choice or necessity--would prefer to spend respite time in their own home. Older children, children with particular needs, or families facing an emergency may benefit most from out-of-home respite services.

Services delivered outside the home can be divided into seven general types (Upshur, 1983; Cohen and Warren, 1985; Levy and Levy, 1986): (1) care taking place in the provider's home, including care exchanged among parents or other caregivers; (2) foster care or licensed family care; (3) group day care; (4) residential respite care; (5) respite care provided in otherwise longer-term care facilities, such as residential treatment centers; (6) crisis nursery or emergency respite care facilities; and (7) generic services, such as schools or camps, through which respite care is provided only as a secondary purpose.

A. Care in the Provider's Home

Cohen and Warren (1985) have described the advantages of respite care services provided in private homes. They note that this type of care can: personalize services, limit the number of persons with whom the child has to relate, expand the social/community experiences of the child, offer the possibility of an ongoing relationship between the child and the individual or family providing respite care, and tend to be economical. Levy and Levy (1986) add to those advantages the flexibility both caregiver and provider have in determining access to and duration of respite care.

One way of providing respite care in private unlicensed homes is the parent cooperative program (Cohen and Warren, 1985; Levy and Levy, 1986; Ferguson and Lindsay, 1986; Ferguson, Lindsay and McNees, 1983). This type of respite service usually involves care exchanged among parents in the providing family's home. In Kalamazoo, Michigan, the Kalamazoo Parent Respite Care Co-op, described by Ferguson, Lindsay and McNees (1983), has demonstrated the positive results a parent organized and operated respite program can attain. The program began in 1977 when parents identified the need for respite services. Following a collaborative planning effort with local professionals, the program was designed so that children with disabilities would receive care in the homes of participating families.

Parents pay no money for respite care. Instead, a staff coordinator keeps track of respite hours given and received by each family. Families are expected to maintain a balance between the times they provide care and the amount of time their children are cared for in others' homes. Care can be provided for as short a period as two hours and as long as thirty days, depending on the needs of families involved.

A "care folder" is maintained for each child with a disability which contains releases signed by parents, as well as information on special care or needs, behavior, favorite toys and activities, and other items. The folder goes with the child when he or she stays with another family to assure that there is continuity and consistency in the care the child receives.

Ferguson and Lindsay note that respite care is frequently used by participating families. New parents, though, usually begin by using only two or three hours at a time, with overnights, weekends and longer stays occurring as they become more comfortable with the program. The authors describe the initial fears many parents have about leaving their child in someone else's home, as well as concerns parents may feel about being able to care for another child with disabilities in their own home. Ferguson and Lindsay also point out the hesitancy of some parents to use respite services if they feel doing so indicates they are less able to care for their own child.

The direct involvement of parents in the cooperative program addresses many of these concerns. Parents new to the program are likely to view those already participating as able to understand their experiences and needs. By sharing information about the program, and demonstrating that they have benefited from respite services, participants can help those just entering the program do the same.

In their description of the parent cooperative program Ferguson, Lindsay and McNees (1983) identified another way parents in the program helped each other. According to those authors, some parents had been uncertain of how to use the time made available through respite services. This was especially true since many had little or no free time following the birth of their child with a disability.

In response, parents began sharing ideas on the ways they used respite time to relax, have fun, pursue interests, or take care of routine tasks and appointments. Workshops are regularly held to introduce newer program members to suggestions on how to use respite time.

Levy and Levy (1986) discuss the advantages of the parent cooperative model, adding to those just mentioned the increased socialization opportunities for the child. Potential difficulties of the parent cooperative model include coordinating the exchanges of care and matching care to the particular needs of a variety of children (both of which are recognized and addressed in the Kalamazoo program). They also note that many parents may already feel overburdened by caring for their own child or children with disabilities and do not feel they want or are able to take on the care of another child with special needs.

Slater (1986) cites as disadvantages of care in the provider's home the difficulty of arranging longer-term care, the possibility of provider burnout since they are also caring for persons with disabilities in their own homes, and the possibility that some families will overuse respite services while others will over provide them. While the authors noted above point out its potential to serve families well, they also recognize that the parent cooperative model of providing respite care may not be suitable or appropriate for all caregivers. A cooperative program, therefore, may be most appropriately organized as a part of a range of respite services.

Both descriptions of the Kalamazoo parent cooperative stress that collaboration between parents and professionals contributed to the program's success. Ferguson and Lindsay (1986, p. 165) also note that this model departs from the traditional practice view of "doing for, not with" parents. This view, they maintain, has accompanied the assumption that parents are "weak, inadequate, and unable to cope." In the parent-operated program, on the other hand, the perception of parents is that they are the experts; they best know the needs of the children and how to care for them.

Another method of delivering respite care in the provider's home is the volunteer family model (Cohen and Warren, 1985). Under this model, families open their homes to children or adults with handicaps for varying periods of time. One such volunteer family program, called Extend-A-Family, is offered by the Parents' Information Group in Syracuse, New York. Typically, a child with a handicap is included in the volunteer family's activities about once a month, allowing his or her family a break from continuous care. The program's goals are to provide new experiences to the child with a handicap, to foster relationships between that child and the host family, and to reduce the isolation the child and his or her caregivers may feel from the community (Parents' Information Group brochure). Currently, the program serves only a few families whose children have emotional handicaps. Staff members, however, see the need to serve those families and are interested in doing so (Michaeline Bendetti, Parents Information Group, personal communication, 1987).

B. Foster and Licensed Family Home Care

Foster or licensed family home respite care typically involves use of trained providers, yet maintains aspects of caregiving in a relatively normalized environment (Humphrey and Labarrere, 1979; Cohen and Warren, 1985; Levy and Levy, 1986). Variations of this type of respite service are described by Cohen and Warren (1985). For example, a program may match provider families with caregivers needing respite. Following the match, arrangements for respite times

and payments are made between the provider and recipient of services without respite agency involvement. A second approach involves the respite agency both arranging respite care in foster homes and paying the foster family. Unless services are free, caregivers receiving services may then reimburse the agency on a sliding fee scale.

Under the program described by Humphry and Labarrere (1979) foster homes are screened and selected by the Children's Home Society in Los Angeles County, California. Families apply for respite services through a county agency for persons with developmental disabilities, and, once authorized, are referred to the Children's Home Society, with whom the county has a purchase-of-service agreement. After the child/foster home match is made, respite services are provided, at no charge to caregivers, for periods of between twenty-four hours and three consecutive weeks.

According to Humphry and Labarrere (1979), foster parents in the Los Angeles program are required to have experience with children, either their own children or through work experience. Of the initial applicants, 80% are not accepted or remove themselves from consideration. Screening procedures and visits to the home by a social worker are used to ensure that prospective foster parents are qualified and acceptable. Foster parent training occurs both during and following these home visits. The agency expects foster parents to work with the child's caregiver in planning and carrying out respite care sessions.

An important limitation of the Los Angeles program is that children with severe behavioral or medical problems cannot be served. Other program difficulties include the insufficient number of approved foster homes and inconsistency in program funding. Levy and Levy (1986) note that regulations in some states limiting which clients can be served in foster care or licensed family homes are another disadvantage.

In their discussion of out-of-home respite, Levy and Levy also describe advantages of providing respite care in foster homes. One of these is flexibility in the length of time care can be provided. Another is suitability to particular clients. For example, older children preparing for residential placement may benefit from foster care stays as part of the preparation process.

C. Group Daycare

Another way of providing caregivers access to out-of-home respite care is the group daycare or day drop-off center (Upshur, 1983; Levy and Levy, 1986; Cohen and Warren, 1985). These programs are generally located in existing facilities such as schools, churches, or community centers and operate during daytime working hours or on weekends. The availability of this type of respite care offers parents relief from caregiving responsibilities for a few hours or a day, and frees them to go on errands, schedule appointments, or simply relax.

Respite times at a day respite center can be scheduled, or, as in the "drop-in" model, used whenever the center is open. Staff trained to care for children with disabilities, which may include behavior problems, provide supervision and planned activities during the child's stay at the center. Tri-County Respite Care, based in Aloha, Oregon, maintains three day respite care centers, one located in each county it serves (Tri-County Respite Care brochure, 1987). These centers, which are open two Saturdays per month, serve children from ages three to eighteen years who have developmental disabilities. A variety of activities are provided, and a staffing ratio of 2.5 adults to each child allows individual attention to be given when necessary. Space for the centers is donated by churches

and a hospital facility. The Tri-County Respite Care program is in many ways typical of day respite centers, although some programs are able to provide services seven days a week.

Cohen and Warren (1985) describe another variation of daycare respite: the family home daycare program. They illustrate this model with a program designed and implemented by the Early Childhood Research Program at Utah State University. This respite care program involves specialized training for licensed daycare families, enabling them to care for children with special needs. This model was found to be particularly valuable in rural areas where transportation to a central location is difficult.

The group daycare model of respite service has advantages not found in most in-home services. These include: (1) socialization opportunities for children with handicaps; (2) availability of structured activities for children; (3) more intensive back-up available than when individual services are provided in a home; and (4) frequent access to respite services, in some cases as often as two or three times a week (Upshur, 1983; Cohen and Warren, 1985).

Disadvantages of the model are: (1) difficulty in serving a wide range of clients, unless groups can be run concurrently for different ages and levels of disability; (2) the possibility of families experiencing difficulties transporting their children to a central location (although some programs provide transportation, this can still be a problem if long distances must be traveled and respite care is provided for only a few hours); and (3) the expense of staffing, space and equipment. Upshur notes, however, that once initial costs have been paid, group care costs can be lower per client than home-based care, particularly if space is donated (Upshur, 1983).

D. Residential Respite Care

The respite residence, or respite group home, offers temporary twenty-four hour residential care to a child with a handicap for the purpose of providing relief to the child's family or other caregivers (Cutler, 1986; Upshur, 1983; Cohen and Warren, 1985; Levy and Levy, 1986). These facilities commonly care for four to twelve clients in a home-like setting. Staff trained to work with the particular disabilities of the client population provide care, supervision, and individual and group activities.

Typically, a child may stay in this type of facility for a weekend, a week or even as long as thirty days (Upshur, 1983). Cutler (1986) notes that programs can be designed so that parents, who may be reluctant to leave their child in a new setting, can place their child in a residence for a few hours or a day. Once they have become familiar with the home and its staff, they may then choose to use it for longer periods of time.

The respite residence is particularly appropriate for young people with severe behavior problems (Upshur, 1983; Cutler, 1986). This is especially true if the child is unable to be cared for by a single respite care provider in the home. Upshur (1982) found that the severity of a child's behavioral difficulties sometimes resulted in his or her family's exclusion from respite services, yet those families were often the most in need of respite. The residential group respite model can address this problem by maintaining trained, experienced staff and a high staff-client ratio. Cutler (1986) recommends two line staff to each child and, further, suggests administrative and supervisory personnel be used on an on-call basis to increase the ratio when needed. This allows for more intensive supervision and effective activity planning, as well as for the occasional individual attention a

child may require. Additionally, clients benefit from the opportunity respite home staff have to get to know them over repeated stays and to develop an awareness of how to deal with specific behaviors.

The respite residence may be designed to offer respite care on an emergency basis. This can be especially comforting to parents during a crisis as they can leave their child with qualified and experienced care providers. Caregivers can then focus their attention on the emergency at hand.

Cutler (1986) notes that the capacity and accessibility of a respite residence present a potential problem. It may be used for clients with less critical needs, who may have access to more appropriate programs. Describing the need for both caregivers and program staff to be clearly aware of who is to be served, she suggests that admittance priorities be established. Cutler (1986, p. 180) recommends admitting clients to the program in the following order of priority:

> (1) clients in medical or other family emergency; (2) clients who have been refused respite care and have no resources beyond the immediate family; (3) clients who have received minimal, marginal, or inappropriate service; and (4) clients with less severe handicaps whose families are in crisis and who have no or limited resources at the time of the emergency.

Also, Upshur (1983) recommends limiting the length of time any one client can be cared for in a respite residence. This would help assure that openings for new clients can be regularly available.

Among the most frequently cited advantages of the respite residence model are the ability to provide more intensive services to clients with emotional and behavioral difficulties, access to backup services, and availability in emergencies (Upshur, 1983; Levy and Levy, 1986; Cutler, 1986). The model does, however, have limitations (Cutler, 1986; Levy and Levy, 1986; Upshur, 1983). For example, the young people receiving care need to be somewhat similar in age, disability, and behavioral functioning. In addition, staff must deal with a constantly changing clientele, making group-building and socialization processes difficult.

Residential respite programming is also much more expensive than home-based care (Cutler, 1986; Upshur, 1983). Cutler regards the possibility that a residential respite service may be more restrictive than is appropriate for many of the clients served as an additional problem. She goes on to say, however, that with respect to both cost and restrictiveness this method of respite care is preferable to the institutional care it may help to avoid.

A variation of the respite residence model, entitled the SEARCH Day Program, operated from 1978 until 1981 in Ocean, New Jersey. Although designed as a day program, the SEARCH facility had beds and a kitchen on the premises. The respite program allowed three students in the day program to stay in the facility over a weekend. Coupled with normal program hours, this meant that families were actually provided respite from Friday morning until Monday afternoon. Regular SEARCH staff provided weekend coverage, which added to the respite program the benefit of pre-existing relationships with the children. The respite program was made available to students and families on a rotating basis.

Both the children and their parents responded very favorably to the program. Over their weekend stay, children participated in gardening, cooking, and educational activities. Parents were charged a fee for the weekend care, but

the program's grant allowed SEARCH to absorb the expenses for parents unable to pay the fee. Typically one out of three parents required financial assistance.

Overall, the SEARCH respite program was innovative and successful. But, as with many grant funded programs, its financial support did not continue and the respite program ended (Margaret Gill, personal communication, 1987). Nonetheless, the SEARCH program demonstrated that respite care could be provided as an adjunct service by an existing agency. Other agencies, particularly those designed as residential facilities, may also carry the potential to provide respite services.

E. Respite Services Provided by Residential Treatment/Care Facilities

Occasionally, programs designed to provide residential care or treatment make their facilities available to families for respite care. Upshur (1983) describes types of facilities that may reserve a few beds for respite services, including community residences or group homes serving adolescents, residential treatment facilities, state institutions, and nursing homes. Levy and Levy (1986) report that many state operated institutions provide respite care on an emergency basis and that some maintain a certain part of the facility specifically for respite services.

There are advantages to using residential facilities for respite services to families. Well trained staff and readily available backup services make them suitable for children with severe behavioral or medical problems, and they are generally accessible when emergencies arise (Upshur, 1983). There are also drawbacks, however, to the use of ongoing residential programs. Families may be reluctant to leave their child in a residential facility, especially if the child must be formally admitted (Levy and Levy, 1986). In addition, temporarily placing children within an ongoing group may be disruptive to the regular residents and the program involved.

F. Crisis Nurseries and Emergency Respite Care Facilities

Crisis or relief nurseries, and emergency respite care facilities differ from most of the programs described here as they are designed to serve families and children whose special needs are not directly related to a child's handicapping condition. They are intended as a supportive service to families who are temporarily unable to care for their children or whose children may be at risk of abuse or neglect. These programs can be crisis oriented, preventative, or both in nature and purpose. Access is determined primarily on the basis of the difficulties the family experiences.

There are similarities between crisis/emergency respite care programs and those designed specifically to care for children with handicaps. For example, Subramanian cites the goals for emergency care as being to provide a safe environment for the child and to provide a non-threatening resource for parents. These general goals would be applicable to any of the programs that have been discussed.

Some elements of emergency and preventative care programs could be applied when planning respite care programs for families whose children have emotional handicaps. In particular, emergency and preventative services normally involve: (1) access on a short-term and emergency basis; (2) staff training on helping children in emotional crisis and/or with behavioral difficulties; (3) coordination with other relevant services; and (4) linkages with other community resources.

Any of these factors can enhance the quality of respite care programming, whether for families facing a crisis or families having a child with a handicap. The immediate purpose of the crisis or relief nursery is to provide relief to parents when family conditions are leading to potential abuse or neglect of their children (Virginia Child Protection Newsletter, 1987, p. 3). Often located in churches, schools or other community facilities, these programs offer care for children and support to families on a daytime or twenty-four hour basis.

One such program, the Lane County Relief Nursery in Eugene, Oregon, has been described by Milne (1986). This service provides a day program for children ranging in age from six weeks to six years. These children come to the nursery twice a week. Most of the children and families served are referred by Children's Services Division, the state's child welfare agency.

Program staff attempt to both ameliorate the effects of abuse and prevent future abuses. The program includes a therapeutic preschool providing educational and other activities designed to ease the trauma experienced by children who have been abused. The children are also involved in activities enhancing their self-esteem and socialization skills. Parents whose children are in the preschool program are provided parenting skills classes, as well as individual or family counseling.

In some cases, children attending the nursery are in foster care placements. Plans for a child's return home may include his or her parents' participation in counseling and parenting skills classes provided by the program. Parents may also spend time with their children at the nursery, where they may benefit from modeling by staff and opportunities to apply skills learned in the parenting class.

Another crisis nursery model is illustrated by the Northland Crisis Nursery in Flagstaff, Arizona. This program provides overnight care and is open twenty-four hours a day, seven days a week. As with many other crisis facilities, referrals often come through churches, social services, friends of clients, or directly from the clients themselves.

The children cared for range in age from birth to eighteen years of age. According to the program's assistant director, as many as half of the children in the facility at any one time are adolescents, and the program includes staff skilled in counseling older children (Curtis, personal communication, 1987). As with the Lane County program, the Northland Crisis Nursery recognizes the importance of services beyond respite care and includes preventative and treatment services, provided at the agency or through linkages with other community resources.

Franz (1980), describing the Emergency Respite Care Center in Madison, Wisconsin, notes that emergency respite care facilities tend to be a blend of several different kinds of services. These services may include temporary shelter, daycare, family counseling, child treatment, and information and referral. Franz also points out the importance of considering the emergency nature of these services in planning; ideally access is based on when families need help rather than when the agency is able to provide it.

In the California Bay Area, staff of the Parent Services Project have recognized the central role planned or emergency child care programs can play in identifying and providing services to families, especially families facing high levels of stress. The project provided planned and emergency respite care programs, and in doing so learned that as parents became familiar with these programs they developed trust in them, and turned to them in times of need. As a result, project staff have expanded the services and activities available to participating parents. Along with respite services, the programs offered include a variety of social events, educational activities, and community services. These

programs are designed to reduce the social isolation, feelings of stress, and other conditions that often lead to serious family and community problems. The project seeks to provide overall support to strengthen families, rather than to focus on a specific area of family need or only be available during times of crisis (Ethel Seiderman, personal communication, 1987).

Models such as that developed by the Parent Services Project demonstrate how a system of services can be designed to best assist children and families. They are useful in identifying ways that respite care can be provided in conjunction with other supports to enable families to function at their best.

G. Generic Community Services as Respite Care

Generic community services are those that are available to the general population and may include recreational, educational, social, or a range of other types of activities. There may be a fee for the services or they may be free. Specific examples include day and overnight camps, school activities, after school activities, organized sports, and arts and crafts classes. While these services do not offer respite for parents as a primary purpose, they do provide parents some relief from caregiving tasks.

Salisbury (1986) has pointed out the importance of making community resources available to families whose children have handicaps. She notes that these resources facilitate participation in the community and often provide the social context within which many families operate. Too often, though, programs are unable or unwilling to include children with physical, mental, emotional, or behavioral problems in their activities. According to Salisbury, when this occurs the social supports of the excluded children's families become constricted, leading to higher levels of stress and isolation and fewer opportunities for relief and renewal. Another result of the exclusion described by Salisbury can be increased dependence of the child with a handicap on his or her family.

Salisbury calls for community resources to be designed so that as wide a range of users as possible can benefit from them, and gives four reasons for doing so: (1) developing and supporting specialized community services is costly, and those services are often of lower quality than generally available services; (2) it has been demonstrated with the elderly and persons with physical handicaps that resources can be modified; (3) the long-term costs to persons with handicaps appear to be greater when only specialized services are available, which presents consequences to all members of the community; and (4) providing integrated services can broaden the social supports and networks of all families in the community.

Caregivers and professionals may need to engage in advocacy work to make community resources accessible to children with disabilities. Ensuring that specialized training is provided to an activity's staffers, for example, could enable the activity to include children with emotional or behavioral problems. Another option could be finding funds for extra staff which would allow children requiring more attention than others to be involved in activities. If funding were available, a specially trained respite care provider could also accompany an individual child, which would allow the child to participate in activities such as team sports. This last method has been used effectively in many public school settings which have used aides who provide one-to-one assistance to children who could otherwise not remain in the classroom.

The important point in relating community resources to respite care is that those resources can only be useful to the children and families who have access to them. Especially when regular respite programs are not available, ways may need to be found to assure that the families who often need relief the most--families whose children have special needs--are able to receive the benefits of programs available to other families in the community.

RESPITE PROVIDERS: ATTRIBUTES AND TRAINING

Leaving a child with an unfamiliar care provider can be difficult for any parent. If the child has special needs, including emotional or behavioral problems, the difficulty may be even more profound. Even when formal respite services are available, parents whose children have handicaps must feel that providers are competent if they are to use those services (Cohen and Warren, 1985; Neef, et al., 1986).

A sense of relief from having a trained person available to care for their children has been cited by parents as one of the greatest benefits of respite care (Joyce and Singer, 1983). On the other hand, parents who have used respite services and felt them to be unsatisfactory have frequently identified inadequate training of providers as a primary reason for their dissatisfaction. Lack of training was a particular problem when the child had severe emotional, behavioral or physical problems (Upshur, 1982).

When parents responded positively to the care their children received, their responses were often closely related to the characteristics of the respite care provider, and to his or her interactions with the child and family (Ptacek, et al., 1982; Joyce and Singer, 1983). One of the respite care programs described by Cohen and Warren (1985) has outlined provider characteristics that facilitate families' perceptions that respite care services are effective and useful. These are: (1) dependability, consistently on time, available when needed, and responsible in carrying out tasks; (2) maintains a pleasant mood, sense of humor, and positive outlook; (3) exercises good judgment and common sense; (4) displays sensitivity, consideration, and warmth toward clients; (5) demonstrates emotional stability and control; (6) ability to move into new situations easily with flexibility, adaptability and resourcefulness; (7) works well with supervisors, co-workers and other agency staff; (8) demonstrates skill in assisting clients with daily living activities and self-help skills; (9) displays household management skills, including food preparation; (10) ability to manage medical routines effectively; (11) willingness to communicate with and listen to family members.

In addition to the above skills, persons providing respite care to children with emotional handicaps need to be prepared for manipulative, impulsive or aggressive behaviors, as well as severe tantrums. They need to manage these behaviors without responding in an overly angry or impulsive way themselves. Some children with emotional problems may be very withdrawn, so respite workers require skills in approaching those children and drawing them into activities. Providing respite care to children with emotional handicaps may also involve working with them to improve social skills and peer relations.

Along with an ability to manage behaviors, the respite care provider for children with emotional handicaps needs an understanding of those behaviors. Having insight into the nature of emotional problems not only helps providers to interact more successfully with a child, but also enables them to work effectively with others involved in helping that child. In addition, knowledge of current views of emotional and behavioral disorders provide respite workers with alternatives to traditional viewpoints (especially parent blaming), that may inhibit successful collaboration with families.

Issues in Assuring Provider Effectiveness

Locating respite care providers with all of the required skills and qualities does not guarantee a successful respite care program. Other factors involved in service planning and delivery will determine how effectively those skills and characteristics can be applied. Cohen and Warren (1985, p. 108) have described six basic processes involved in respite care programming that can influence the perceptions parents will have of respite providers. These are: provider selection, recruitment, training, matching of respite workers and families, supervision of respite providers and evaluation of worker effectiveness and competence. Consideration of these processes, and attention to the concerns raised by parents' responses to them, will have significant influence on the design of respite care programming. How each process is approached, however, will be largely determined by the perceptions program planners, managers and users have of respite care providers.

Approaches to Recruiting and Maintaining Respite Care Providers

Respite care workers can be seen as unpaid volunteers whose primary motivation is helping; or as trained and paid professionals or paraprofessionals who have access to career advancement, adequate pay, and ongoing training. Both views can be found among those working to develop respite care services (Cohen and Warren, 1985). They are not necessarily, however, mutually exclusive. Given the pay scales most often offered to respite workers (Slater, 1986), there can be little doubt that even paid workers are motivated to help. And when volunteers are used to provide respite care, incentives such as academic credit can be built in to increase provider commitment.

Although advantages have been found to both paid and volunteer models of respite care, there is an increasing emphasis on adequate payment--even certification--for respite workers (Parrish, et al., 1986). As the respite care field allows for career and personal growth, there is likely to be greater consistency, employment longevity, personal satisfaction, and competency found among workers (Parrish, et al., 1986; Shettle, et al., 1982). This writer's review of existing respite care programs indicated that many program managers are recognizing a need to adequately pay respite providers. Overall limitations in program funding, though, often make this difficult to do.

A. Volunteer Model

Slater (1987) has noted the difficulty respite care programs often face in maintaining a consistent supply of respite care providers. Given the widely varying hours and conditions in which respite care may take place, and the challenges of caring for a person with special needs, it is not surprising that direct service staff turnover is very high. This is especially true when respite care is provided on a strictly volunteer basis (Cohen and Warren, 1985). Accordingly, some form of mutual commitment between volunteer provider and respite care program is essential.

The R and R Program, which provides respite care to families in Spokane, Washington, has addressed this issue by using college students from nearby Whitworth College as respite care providers. Students participate as part of internship programs offered through the school's departments of social work,

education, and nursing. Academic credit is given by the college for time spent providing respite care.

The students care for children, many of whom have emotional or behavioral problems, over a weekend in the child's own home. Training and supervision are included as part of the student's overall instructional program. In addition, students often work in teams, which allows for further support in the respite care setting. These factors contribute to the likelihood of students continuing their involvement when faced with the expected stresses and difficulties of caring for children with special needs.

No money is exchanged by either recipients or providers of respite care in the R and R Program. The program model does, however, include other kinds of benefits. Participating students receive academic credit and are able to gain experience working with children who have special needs--often a critical factor in making career choices. Program coordinators and parents are assured that there will be a number of respite care providers available for a specified amount of time.

This model, in which there is mutual commitment and benefit for both program and provider, has the advantage of being consistent and stable--the R and R Program has been in operation for seven years and is Whitworth College's largest internship program. It also is an inexpensive model because providers are not paid.

For respite services to be comprehensive, alternatives to the volunteer approach should also be considered in order to promote program stability. In the R and R Program, for example, while the overall number of respite care providers is stable, many of the individual providers change after an academic term or year. R and R Program planners have not limited the source of providers to students--prospective adoptive parents and other volunteers have also been used. But, as with other volunteer models, the amount of time a provider can receive training and, perhaps more importantly gain ongoing experience, remains limited. It is likely that the only way to assure consistent access to highly qualified and experienced respite care providers is to formally train and pay them (Parrish, et al., 1986).

B. Paid Provider Model

The Francis Tuttle Vo-Tech Center in Oklahoma City, Oklahoma, is developing a respite care provider training curricula within existing health and child care programs. Working in conjunction with Oklahoma Child and Adolescent Service System Program (CASSP) Director Rock Richardson, and the parent advocacy group Positive Reflections, Inc. the school is seeking to include training for respite care work with children having emotional handicaps.

Families Together, Inc., located in Topeka, Kansas, is developing respite care training curricula for providers who will work with children having emotional and behavioral disorders. Under the program, Families Together will identify existing curricula designed to train respite care providers to serve families whose children have disabilities. Those curricula will then be adapted to include specific skills needed to work with children and adolescents who have emotional handicaps. The program's planners hope the training will allow providers to function as paraprofessionals. The program received state funding during 1987 and is currently being implemented.

At least two community colleges in the state will serve as demonstration sites for the training curriculum. Once the curriculum is in place at those facilities, further training and consultation will be provided to instructors by

Families Together. The project will also include recruitment of students and some scholarships.

The respite programs we reviewed seldom paid direct service providers more than minimum wage. Barbara Huff, of Families Together, has noted that persons who have completed the planned training curriculum should receive a higher wage. Programs such as that being developed by Families Together recognize the importance of the high levels of training, even certification, that have been recommended for respite care providers (Salisbury and Griggs, 1983). Parrish, et al. (1986) have described several advantages to formal certification for respite care workers. Among these advantages are:

(1) The development of a certification process may lead to an overall review and determination of respite care resources and needs, as well as an assessment of what skills are needed by respite care providers. This could lead to an increased pooling of resources and objective evaluation of required provider competence;
(2) Certification, especially if it involves continuing education, may ensure that providers stay updated on current service knowledge technology;
(3) Certification may raise the status of respite care providers, attracting a higher number of skilled and talented individuals. This would offset the chronic staff shortage often experienced by respite care programs;
(4) Coverage of respite care services by third-party payments and private insurers would more likely occur if providers were certified;
(5) Respite care providers paying annual certification fees may be more likely to provide services more often; and
(6) The monitoring and evaluation functions of certification would serve to uphold and maintain standards of care.

Certification and other procedures designed to maintain consistently available, qualified respite care providers will be most meaningful when there is stability in the provision, maintenance, and availability of respite care programs. That stability is dependent on public policies providing for support, especially funding, to programs serving families caring for children with disabilities.

RESPITE CARE AND PUBLIC POLICY

With the implementation of the deinstitutionalization and normalization movements, especially in the field of services for children with developmental disabilities, respite care became an issue of public policy (Castellani, 1986). Respite care was seen as one of a range of services that enable families to care for children with disabilities in their homes and thereby reduce the public's responsibility and costs in providing care for those same children in institutions. As a policy issue, respite care is often placed in the context of family support services. In addition to respite care family support services may include transportation, financial assistance, family counseling, parent training, or recreation programs. These services focus on the family rather than the individual with special needs and are designed to achieve the objectives of "strengthening the family" (Castellani, 1986, p. 290), and minimizing "potentially harmful stresses affecting the family" (Moroney, 1986, p. 28).

Public policies have not, however, provided for sufficient development of supportive services such as respite care. For example, eligibility for respite care is often linked to the occurrence or imminent risk of out-of-home placement, which causes many families to be excluded from receiving services (Castellani, 1986). Sullivan (1979, p. 114) has described how this situation affects families of children with autism:

> Most parents of autistic children want to keep their child at home as long as possible and feasible. Yet most states will spend $10,000 to $50,000 a year to place a child in a state institution or on out-of-state residential facility, but refuse to grant a few hundred dollars a year to relieve the family of unending front-line fatigue. In New York, families are offered a stipend to take their autistic child out of the state hospital. There are no funds, however, for parents whose children are at home and have never been institutionalized.

Sullivan suggests that the answer to this dilemma lies in society's approach to social welfare policy. That approach can either hamper or facilitate increased provision and availability of respite care services:

> The cure for lack of respite is known, yet there is still a tremendous psychological resistance to the idea that the state has a moral responsibility to help families who need respite services.
>
> If we think of government as an extension of persons and families, providing for us, by our permission, what we cannot do for ourselves as efficaciously (e.g., roads, bridges, schools, parks, postal service, airport terminals), then we should have no problem in expecting government to provide to families in a crisis, *no matter how long*, what it does routinely and daily for other citizens' convenience and pleasure. (Emphasis added).

Moroney (1986) has demonstrated that social welfare policy in the United States does not view support services as a right that should be extended to all families. Rather, his assessment of recent approaches to family support policy indicates that the primary perspective has been one of minimum recognition for societal, and therefore governmental, responsibility for adequate support to families.

Moroney (1986, p. 161) describes the concept of "shared responsibility" between families and government, and makes it clear that, as in any mutual task, true sharing is not limited to crisis intervention. Instead, however, current family support policy often assumes that government must step in because families have failed and have not been able to carry out their part of the task (Steiner, 1981). As Cohen and Warren (1985, p. 12) have pointed out, this perspective omits significant realities:

> What has not been reflected in this equation is the recognition that special circumstances, such as the presence of a severely disabled child, can lead to an overload of responsibility on the family unit, and that even healthy, functional families may need support in view of this excessive burden. To use such support systems under these circumstances is not a sign of family failure. It may be a sign of a family's drive to maintain health.

Inconsistencies in funding and policy support for services to families whose children have handicaps are especially evident in deinstitutionalization policies. Even though deinstitutionalization has brought increased pressure onto many families, it has not been balanced by an expansion of community and family supportive services (Moroney, 1986). In fact, "of the possible community alternatives, residence within the natural family is the least supported with both dollars and services" (Cohen and Warren, 1985, p. 86). In other areas, while overall social welfare expenditures have increased over time, little of the increase has gone into services specifically for families whose children have disabilities (Moroney, 1986). When funds are available there tend to be restrictions on their use. These restrictions severely limit which families will benefit. In the field of child welfare, for example, the bulk of the dollars spent are restricted to families with very low incomes or for children in out-of-home care. Therefore, the majority of families providing care to children with handicaps are excluded from services--not because they don't need them--but because they are not poor enough (Moroney, 1986).

To demonstrate the low priority given to services to families, Moroney (1986) listed ten services that could enhance the families' abilities to care for children with special needs and noted that these account for less than ten percent of Title XX social services expenditures. Further restricting their availability was the fact that they are most often provided only to families with low incomes. In the sample cited, 98.9% of families using daycare were recipients of income maintenance or were income eligible. Further demonstrating the limited access to services for most families, Castellani (1986, p. 294) cited a survey of family support services, including respite care. In this study, the authors found that, of seventeen states, eight required that risk of out-of-home placement be established as a condition of service and nine states limited service by levels of family income.

Implementation of Current Policy

Social values and policies are eventually implemented in programs and services which are delivered to clients who bear the final impact of policy. According to Cohen and Warren (1985, p. 12), the services resulting from a limited and selective approach to family support have been inadequate to meet the needs

of families whose members have disabilities as well as families in general. Among the factors they describe as characterizing this inadequacy are the following:

- *Services to families are poorly funded.* Home-based services, for example, have received less than one percent of the total federal expenditure for health and social services.
- *Services to families are fragmented and uncoordinated.* Families must often deal with several different funding and service agencies in order to obtain support they need.
- *Services often are not designed to help families stay together.* Foster care or other out-of-home placements may be provided when homemaker service would serve just as well without breaking up the family.
- *Services are too often provided outside the home without the secondary supports needed to enable families to use these services.* Transportation is one example of a secondary support that is often lacking.
- *Services are often only made available after serious damage has been done rather than to prevent such damage.* Lip service is given to the idea of the family as the basic service unit and to prevention as an important goal, but these concepts are implemented very poorly. A rational system of support would stress services to prevent family disintegration, provided in such a way as to disrupt family life in the least.

As a result of these conditions, when respite services are needed most families find respite care in short supply or too costly. Without respite and other supports many families are placed in a difficult bind. They are told that their child should not be in out-of-home care, yet are provided with insufficient resources to maintain the child in the home. Eventually, placement may be sought primarily because the family's resources have been exhausted (Cohen and Warren, 1985). This may be especially difficult for families whose children have emotional or behavioral disorders. Since the child's disability is less evident than is the case with mental retardation or physical handicaps, and since parents have often been "blamed" for a child's emotional or behavioral problems, placement of the child away from his or her home may be perceived as pathology or failure on the part of the family.

In some cases, policies designed to provide respite care services have been developed but inconsistently supported and maintained. As an example, when the state of Washington established the Division of Developmental Disabilities in 1976, a policy was introduced calling for the availability of respite care to all families registered with the division. From 1985-1987, however, the level of funding did not keep pace with client need. As a result the division has not been able to provide respite care services to all registered families. Respite care eligibility is now based on critical need, crises the family is experiencing, or imminent risk of placement for the child. As a result, many families who could benefit from respite care services--and had previously been receiving them--no longer have access to these services. An additional impact of restrictions on eligibility has been that families must tolerate more intrusive questioning by division workers. This has been difficult for families and workers who had not previously been required to discuss such things as family stress levels in determining who would receive services (Mozena, personal communication, 1987).

Moroney (1986) has identified two key elements for addressing these service delivery problems. He maintains that supportive services such as respite care can only make a significant difference if current eligibility requirements are changed;

supportive services must become broadly available and accessible to as many families as possible. Furthermore, the development of adequate and effective supportive programs will not come about only through better management, but will require a substantial increase in resources.

Respite Care Policy: New Directions?

In order for respite care services to become an ongoing support to the many families caring for children with disabilities at least three fundamental conditions will need to be in place: (1) the existence of an adequate supply of high-quality services that match the number of families needing them; (2) services available to families in a manner that allows access when they are most needed, and facilitates prevention of further problems; and (3) services that are consistent and reliable over time, with families and program staff able to feel secure that respite care services will be continuously available and not dependent on short-term grants or projects. Clearly these conditions necessary for sufficient provisions of respite care services are not yet in place.

The instability of respite care as a support to families was illustrated in 1987 when we followed up descriptions of innovative respite care programs and found that three of them no longer existed. Reasons for these programs' closings included lack of consistent funding (SEARCH, 1987), competition for scarce funds (Cutler, personal communication, 1987), and dependence on hard-to-find volunteer providers (PLEA, 1987). It is also discouraging to see well-intended respite care policies, such as Washington State's, become limited in their impact over time because of inadequate levels of funding to meet the needs of families.

In promoting the conditions necessary for the development of respite care services, policymakers and program planners must address many policy issues that will affect the delivery of services to families. According to Castellani (1986), these policy decisions include:

(1) where services take place (in-home/out-of-home);
(2) accessibility of services to families;
(3) which families are eligible for services;
(4) whether services are delivered through private or public providers;
(5) whether there will be free services, cash payment for service, for vouchers; and,
(6) the degree of family input and discretion.

These issues, as well as the larger one of government's responsibility to provide support to families, are being considered in the literature, as well as in debates over public policy. In the meantime efforts are being made at many levels, from local advocacy groups to federal legislation, to bring about an integration of respite care into the service delivery system. Some of these efforts directly affect children with emotional handicaps and their families. Those that do not (legislation providing services in the area of developmental disabilities, for example) nonetheless serve as models for programs and policies designed to meet the needs of families who have children with emotional handicaps.

A. Local Policies and Programs

In Washington, D.C., every family who has a child with mental retardation is assured, through the district's "Mentally Retarded Citizens Constitutional Rights and Dignity Act" (P.L. 2-137, passed in 1979), of 42 days of respite care in a twelve month period. If further respite time is necessary it can be pursued through court authorization. The act also calls for the District of Columbia's Department of Human Services to develop regulations and guidelines for the delivery and quality of respite care services (Davis, personal communication, 1987).

The Parent Services Project (PSP), with programs throughout California's Bay Area, has established a wide array of supportive services for families including respite care. Eligibility for services is based on the criteria for use of participating child care centers, which means that primarily families with low and moderate incomes are served. Children with disabilities are mainstreamed into daycare programs and are thus eligible for PSP services. The PSP model is very appropriate for families whose children have any type of handicaps including behavioral and emotional problems. The project is designed to strengthen families whose informal social supports have not been sufficient to meet all of their needs, a particularly appropriate goal "in this era of diminishing resources and families in transition."

> Services are designed to meet the needs of single-parent families, working mothers, diverse ethnic populations, parents in educational and vocational programs, and households that are at-risk because of high stress on the parents. Services include sick-child care, parent respite, mental health workshops, community service referrals, training in parenting skills, social gatherings and family outings, and a fund for parent-determined options. PSP parents have substantial control over developing program policy and determining activities (Parent Services Project, 1986).

The cornerstone of the Parent Services Project's philosophy is the following:

1. Preventing mental, physical and emotional stress on parents and children is the most humane and cost-effective way to build strong families today and healthy, productive citizens tomorrow; and
2. One of the best ways to assure the health and well-being of children is to assure the health and well-being of their parents (Parents Services Project, 1985).

Although privately funded by a variety of foundations, the Parent Services Project has relevance to public supportive service policies. One reason is that the PSP can serve as a model for the development of state and federal family support policies. It can also demonstrate to policymakers the long-range benefits and cost effectiveness of providing consistent, comprehensive, and responsive services to families. This process has already begun through a study of the PSP by San Francisco's Center for Human Services which found that for every family served by the PSP the state could save $240 a year in various benefits and services--a potential savings of $4.9 million annually (Parent Services Project, 1986).

The Parent Services Project also influences public policy by actively advocating for legislation that would provide for state-supported services. By

demonstrating the history of effectiveness of their programs, the project's staff and supporters can have a significant impact on legislators.

B. Efforts in and by the States:

The Parent Services Project supported the Parent Services Bill (SB 1308) during the 1987-1988 California legislative session. Unfortunately, the bill died in the Appropriations Committee. The bill would have funded parent support programs in child development centers statewide. The legislature previously passed two family support bills that were vetoed by Governor Deukmejian. SB 1308 called for the annual appropriation for $500,000 for parent support services. The bill allocated funds to child development centers, which would receive $250 for each family served, up to a maximum of 2, 000 families statewide. Eligibility for services was to be determined by state criteria for use of participating child care centers, which target families with low and moderate income. The bill specifically called for respite care to be included as one of the available services (State of California, Senate Bill 1308, June 18, 1987).

In 1987 the Maine legislature allocated $75,000 for family support through the state's Bureau for Children with Special Needs. This includes $65,000 for respite care to families whose children have handicaps, including children with emotional handicaps, and $10,000 for other support services. Passage of this allocation did not come without strong efforts on the part of respite care advocates, especially staff from the Maine Respite Project. Project staff arranged for fifty parents whose children have disabilities to attend legislative hearings, testify on their needs for respite, and describe benefits they've received from respite services in the past. Efforts are continuing in Maine to increase these funds, particularly by providing legislators with clear evidence of the "dramatic need" for respite services (Norton, personal communication, 1987).

Advocates in Wisconsin are preparing model legislation that would provide respite services to families whose children have developmental disabilities, emotional handicaps, or are at risk of abuse or neglect. The proposed legislation would also establish guidelines to assure that respite services are provided throughout the state and are of consistent quality. Part of the impetus for initiation of the proposal by its supporters, and a demonstration to the legislature of the need for its passage, has been the "devastating waiting lists" of respite care programs (Lapacz, personal communication, 1987).

In some states, family subsidy programs that provide cash payments to families whose children have developmental disabilities have been implemented. Subsidies can be used to pay for needed services including respite care. Although these programs have been reported to reach only a small proportion of eligible families, they have resulted in clear benefits to families and the public. Nonetheless, their availability and dissemination remains limited (Cohen and Warren, 1985).

While efforts to promote respite care in the states are encouraging, Cohen and Warren (1985, p. 98) report that similar efforts in the past have been characterized by slow progress and inconsistent maintenance. Some legislation has even served to limit certain types of respite care. Strong lobbying and advocacy are needed to strengthen state legislation and assure consistent funding and support beyond short-term or demonstration projects. Legislation should provide services to a wide range of families without income restrictions or a requirement that families be in crisis.

C. The Federal Level: Final Responsibility?

Respite care has gained some recognition by federal policymakers as a needed service. This has been most evident, perhaps, in the Medicaid Home and Community-Based Services Authority, which allows states to use Medicaid funds for respite care in certain individual circumstances (Cohen and Warren, 1985). However, Medicaid waivers are only provided on a selective and "critical need" basis--often related to risk of institutionalization. They do not reflect a universal commitment to supporting families through respite care.

Federal funds specifically for respite care services have been provided by the Department of Health and Human Services Coordinated Discretionary Funds program. In April 1987 five programs were granted funds to initiate or expand respite services. These programs included crisis nurseries for children at risk of abuse and neglect, as well as programs providing respite for families having children with disabilities. Two of these programs, located in Missouri and Virginia, are using their grants to expand target populations beyond children with developmental disabilities. In particular, they identify families whose children have emotional handicaps as needing respite care services and make services available to these families. These two programs are the Judevine Center for Autistic Children in St. Louis, Missouri, and the Association for Retarded Citizens in Norfolk, Virginia.

Another promising initiative on the federal level has been the Child and Adolescent Service System Program (CASSP), which provides funds to selected states for development of services to children with emotional handicaps and their families. CASSP staff and state directors have demonstrated a strong concern that the needs of families be recognized and that families be included in planning services. At a national CASSP state directors' meeting in March 1987, respite care was identified as a major priority; and, in October 1987, the Oklahoma CASSP Project co-sponsored a meeting of parents from several states in order to gather their input on the development of respite care services.

In the Spring of 1987 the Senate and the House of Representatives passed P.L. 99-401, the Children's Justice and Assistance Act. This act includes provisions for several child care programs including temporary care for handicapped and chronically ill children, and crisis nurseries for children at risk of abuse or neglect. Surpassing the expectations of many of the bill's supporters, the Senate called for fifteen million dollars and the House ten million, specifically for respite care services. However, during1987 the Subcommittee on Labor, Health and Human Services, and Education of the Committee on Appropriations was to determine whether funds would be appropriated and at what level. The Omnibus Budget Reconciliation Bill was passed on December 22, 1987, under threat of cessation of government operations. The final appropriation for respite care services, reduced to $4,787,000, is to be divided evenly between crisis nursery programs and respite programs for families having children with disabilities (Kagan, 1987). According to section 205(d)(2) of the act, eligibility criteria parallel those of section 602(a)(1) of the Education of the Handicapped Act (P.L. 94-142). These criteria include children with emotional disabilities.

Although passage of the Children's Justice and Assistance Act is very encouraging, services will be provided through demonstration programs. There is as yet no commitment to consistent, long range funding for respite care. In order for that commitment to be realized, respite care must be made available through universal social insurance programs, expansion of Medicaid programs, or expansion of noninsurance programs and Title XX personal social service ammendments

(Moroney, 1986. Universally available respite care could be modeled on the Constant Attendance Allowance (CAA) provided in the United Kingdom to families caring for children with special needs or on similar programs found in most industrialized western countries. To do so, however, would call for major changes in this country's social welfare policies. Our policies must reflect an understanding of the special burdens and stresses faced by many families, a value of society and families sharing responsibility for the care of children with special needs, a belief that caring for children is an important task and that all families are universally entitled to assistance in carrying it out; and, perhaps most importantly, that all of society benefits when families are enabled to function at their best.

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